Disability Visibility Podcast

Episode 26: Future of Independent Living

Guests: Allie Cannington and Eli Gelardin

Host: Alice Wong

Transcript by Cheryl Green

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Introduction

[radio static, voices singing with hip-hop beat]

LATEEF MCLEOD: This is the Disability Visibility Podcast with your host, Alice Wong.

ALICE WONG: Hello my friends! Welcome to the Disability Visibility Podcast, conversations on disability politics, culture, and media, I'm your host Alice Wong. Today's episode is on the future of independent living with my guests Eli Gelardin and Allie Cannington.

Independent Living is a philosophy and a movement driven by people with disabilities that started in the 1960s. As a result, Centers for Independent Living formed to provide peer-based services with hundreds currently all over the United States. Eli and Allie will describe what CILs do and their role in disability communities across the country and world. They'll also discuss current challenges and their vision for the future independent living. Please note: CILs are also known as Independent Living Centers but I'll be using the term CIL throughout the interview. Also, this episode was recorded last fall so Eli is referring to 2017 when he talks about something that happened this summer.

[electronic beeping]

ELECTRONIC VOICE: 5, 4, 3, 2, 1.

ALICE: Are you ready? Away we go!

Allie and Eli, thank you so much for being on my podcast today!

ELI GELARDIN: Well, Alice, it just an absolute pleasure to be on your podcast. I think we're both huge fans.

My name is Eli Gelardin. I'm the Executive Director of the Marin Center for Independent Living, one of the 28 Independent Living Centers in California. I got involved in Independent Living 15 years ago and have been a advocate and a service provider ever since.

ALLIE CANNINGTON: Yeah, thank you so much, Alice, for having Eli and I. So, I'm Allie Cannington. I use she and they pronouns. I'm a local organizer and advocate here in the Bay Area. And I first got my start in Independent Living when I had the honor and privilege of being a part of California's Youth Leadership Forum for students with disabilities, which takes juniors and seniors in high school with all types of disabilities, and we go through a few-day program, which is all about disability identity, culture, community.

I really did not wanna go at all 'cause I had so much shame, both as someone with a physical and mental health disability. But to my surprise, my whole world transformed, and I had to continue what came about for me at the Youth Leadership Forum and interned at Eli's center! So, I was the first youth intern at the Center when I was 17. Interning at Eli's Center was the catalyst for me eventually doing statewide and then national work at the National Council on Independent Living, where I was their first Youth Transitions Fellow.

ALICE: Wow. And currently, you're not involved in the CIL world. Is that correct?

ALLIE: Not officially, no, but my first go-to as a local organizer and advocate is to Independent Living Centers and building relationships between folks working in the Independent Living Movement and then also other areas of the disability community, and also other social justice organizations.

[mellow electronica]

Strengths and importance of Centers for Independent Living

ALICE: There's a really rich and proud history of the Independent Living Centers in the United States. It first started in the 1970s in Berkeley, California, to currently hundreds of CILs in every state. So, I'd like to ask both of you, what are the strengths of CILs, and why are the important for the disability community?

ELI: As you said, Alice, Independent Living started basically 40+ years ago out of a fundamental need for individuals with all types of disabilities to establish their civil rights. And it was really modeled after the Civil Rights Movement, the Woman's Movement. Our predecessors fought hard just to gain access to school, to employment, to healthcare. It's ironic, of course, that 40 years later, we are still fighting for that fundamental access to those services and to those resources.

We established Centers based off of core services and funding that started out of Washington D.C. While we've made great strides in many areas, one of the challenges is we have not dramatically expanded that funding. And when you look at the population, really, across the nation, and we see the percentage of folks with disabilities, and you look at the service provision that we provide, the resources don't meet the demand.

ALICE: And Allie, you've had a perspective from the local, state, and national level. So, tell me what you've seen and what you've witnessed in terms of the power of CILs and the importance of CILs.

ALLIE: Independent Living Centers have to be 51% run by people with disabilities. And so often in society and growing up, people with disabilities are assumed to be the ones who are being given the services. Which is totally awesome and fine 'cause we all need services and support. And though, I never thought until Independent Living Centers that people with disabilities could also be leading those organizations. The peer-run model of people with disabilities, we are the experts on disability. And so, the model is nothing about us without us, that people with disabilities have to be at the table leading organizations that are not only serving and supporting people with disabilities but creating political and social change to create more justice for people with disabilities.

In a lot of cases, in order to receive services at a disability organization or service provider, you have to have proof of your disability. And my understanding, if it still stands, is that you do not have to have documentation to "prove" your disability in order to receive services in

Independent Living. And that equates to the importance of self-identification as a person with a disability. It opens up the door to folks who may not have access to documentation, whose documentation may not actually reflect their current disability needs. And so, it really opens up space to be more inclusive to the diversity of the disability community.

[mellow electronica]

Systems change advocacy

ALICE: One thing I think is really key to CILs, and one thing that I always associate with CILs, is systems change advocacy. And I guess for people who have kinda never heard of that term, what is systems change advocacy?

ELI: Systems change advocacy is really the concept of changing the way our culture, our community, changing the way we operate, changing social norms, changing systems that were traditionally built to benefit some and oppress or marginalize others. Systems change advocacy involves community organizing and bringing together, in Independent Living's case, the disability community to share and advocate from a peer perspective. And when we look at systems change advocacy today, there's no greater model in my mind than some of the work that was done over the summer with ADAPT, with NCIL, and with the Independent Living Centers across the country around healthcare. Instead of policy makers telling us how we should or shouldn't take care of our health and our bodies and deciding for us, we took the power. We took it in our own hands, and we said, "No. Actually, this is what healthcare means to me. This is what Medicare, what Medicaid means to me. And you need to hear from us. We have the lived experience."

ALLIE: So often, people with disabilities, we're put in our silos based on diagnoses, and Centers for Independent Living model cross-disability service and advocacy. Independent Living Centers bring all kinds of people with disabilities together.

ELI: We learn so much from each other. It brings us towards commonalities but also understanding each other's uniqueness. When you look at the history of disability rights, and when you look at what Independent Living has done whether it's the Americans with Disabilities Act, whether it's IDEA for children and youth, developing Individualized Educational Plans in schools, whether it's access, whether it's healthcare, it really has to come from a cross-disability perspective and from a systems change perspective.

ALICE: Yeah, and I think that CILs are often the very first entry points for a lot of people with disabilities to see cross-disability advocacy but also, more importantly, this understanding of disability as a political and social identity which goes beyond the medical model. So, I feel like CILs really have a really important role in terms of just sharing disability culture as well.

ELI: I look at folks like Allie, and I look at other emerging voices who've come to the forefront in the last few years. You need that community to lift voices up. And when you utilize a network of multiple Independent Living Centers, multiple communities, and multiple states and even countries, you create power.

ALICE: I also wanna say, as a young leader in the movement, I hold privileges being white, access to a college education, upper middle class. I have certain access and privilege in these spaces that I think is really important to name. With that being said, the power of community that Eli is talking about, although it took some time for me to fully feel that, when I did, during some of the darkest times in my life, I was surrounded by folks in the Independent Living Movement, and I just have vivid memories of wheeling up to some of the comrades from Centers for

Independent Living across the states and just going to hug them and feeling like I was home. And feeling that comfort and knowing that they would accept me and hold me during the grief that I was going through at the time. I think that speaks to the potential of what a loving community can feel like.

Often in the work that I do is really engage folks who are members of the disability community but don't know that their community exists. I just want to be engaging and bringing more people with disabilities into the knowledge that they have rights, that they can be in charge of the decisions they make about their bodies and minds, and that there are places that can support them as individuals with disabilities in pursuing what they need to pursue. I believe there's real potential of the ways that Centers for Independent Living can partner with healthcare providers, other service providers to really model peer-run services, person-centered care and advocacy. For me, it's like building out a larger movement. And so that more people know that they do not have to be alone and in isolation of experiencing disability and that it can be seen as an essential, beautiful, natural part of human diversity. And where we would be without disability, I don't know, and I wouldn't wanna know. 'Cause it's an essential part of the fabric of our whole society.

ALICE: Great. Thank you, Allie.

[reverberating electronica]

Today and the future for CILs

ALICE: I wanna ask you both, what do you dream and think about in the future for CILs? And what do you wanna see in the future, and what do you wanna see today?

ELI: When I think about the future, I actually go back to the past. And where I go is the founders of Independent Living: Folks like Judy Heumann, Ed Roberts, Micah Bristow, Lois Curtis, Elaine Wilson. They were creating new ways of advocating and doing business and challenging norms and challenging structures and systems. And I firmly believe that that is the space where Independent Living Centers thrive. It's through creativity, entrepreneurship, advocacy whether it's in healthcare. Whether it's in employment, whether it's in civil rights, we need to continue to challenge ourselves to push forward. So, when we look at technology, for example, and all the access opportunities that have begun to be integrated into wireless technology, whether it's cellphones or plugged-in cars or other new technology, there's an opportunity for collaboration and innovation there with Independent Living Centers. And I know, for example, here in the Bay Area, many of my peers have been collaborating with start-ups and technology providers to spur and build innovation.

ALLIE: I think that to think about the future of Independent Living is to also identify serious areas in need for improvement. First and foremost, it's that the leadership of a majority of Independent Living Centers and the leadership of a lot of the Independent Living Movement does not look like the majority of people with disabilities. There's a lot of white leadership, folks with physical disabilities particularly, which does not reflect the immensely diverse community. Disproportionately, disability is within communities of color, and we are not, as a movement, we are not acting in ways that are anti-racist. And we, myself included, have a responsibility to ensure that disabled leaders of color are given credit, as they have always been a part of this movement; they've always been leading it. Nothing about us without us: If we're gonna say that about disability, then we need to say that about other parts of our disability community, which includes race, gender, sexuality, documentation status, immigrant status, class. The list goes on and on.

Particularly right now, but at any point in our history, every issue, including a racial justice issue, is a disability issue. And so, one thing that I've really struggled with is to see the Independent Living Centers be silent around issues of police brutality, facing particularly black, but black and brown disabled folks when over 50% of people killed by police are black and brown disabled folks. So, realizing that those individuals who are killed by the police, those individuals who are black and brown, D/deaf and disabled folks are also consumers at Independent Living Centers, and that Independent Living Centers have a responsibility to build with other organizations in pursuit of social justice.

And I really, as a young person in this movement, have been pushing organizations--the National Council on Independent Living and local Independent Living Centers--to do better. Because we can always do better. And I just want to uplift the We Can't Breathe project which was initiated through the diversity committee at the National Council on Independent Living and headed by Dustin Gibson and Keri Gray. And this was a project that created a tool for Independent Living Centers to facilitate conversations around racism and police brutality towards people of color with disabilities.

ELI: To Allie's point, I think one of the best things that we, who are already in Independent Living could do is to give voice and power to the younger folks and folks from under-served and under-represented groups. So, whether that's having a Board of Directors, appointing people in leadership positions, putting strategies into place to ensure that not only are we looking for the next generation of strong leadership but that that strong leadership represents under-served and under-represented communities. And just one more component to this, which is just so relevant today: We're also talking about the caregiving and service provider population that also represents under-served and under-represented community members. Whether it's our caregivers or folks who work in the healthcare industry as medical assistants, janitors, whatever level, we're talking about marginalized communities that really need to be lifted up along with our broader disability community.

[reverberating electronica]

ALLIE: An example of when, as a member of the Independent Living Movement, I was disappointed and really saw room for advocacy was when Mike Brown was murdered by the police in 2014, and I was working at the National Council on Independent Living at the time. From the national to local level, there was silence from the disability community, the Independent Living Movement, about the horrific nature of what was going on in Ferguson. And as a result, myself, Ki'tay Davidson, and TL Lewis started the #DisabilitySolidarity, which was really to hold the disability community—including the Independent Living Movement—accountable for pursuing and striving for racial justice and responding, preventing and responding to issues of racial injustice that deeply face black and brown folks with disabilities. And it also shouldn't have to be a disabled person for the disability community to speak up because until all of us are free, none of us are free. I believe that other phenomenal leaders of color in the Independent Living Movement are paving the way, and I really hope and believe that we're moving towards a space where there is greater amounts of disability solidarity.

ALICE: I definitely see within the last three years—and you said 2014—in the conversation today, it's, I think, definitely a little bit different. Because I see disabled people of color much more like, "This is not acceptable." And they're being really unapologetic about it. I think that's really, that's part of the greater sense of accountability that not just CILs but other people in the disability community that we think of as leaders really need to listen and respond.

ELI: I think we have to be really honest with ourselves and our assumptions. Just because we are people with disabilities, it doesn't mean we don't hold our own internalized oppression and prejudice. When you look at this last election, and you look at the states that swung the election, most likely the disability vote actually impacted that decision, and people were voting—or at least a portion of folks with disabilities were voting—against their most likely personal interests and voting for social interests, whether it be this form of isolationism and marginalizing immigrant and populations of color. And so, I think it's not just the Independent Living community, but we, as people with disabilities, really have to self-reflect on what our values are and what our perceptions of society are, whether it's disability, race, gender, any under-served or under-represented population.

[upbeat, lighthearted guitar]

ALICE: Any other final thoughts about the future and just anything else you wanna share before we wrap up?

ALLIE: I dream of a world where Independent Living Centers reflect in their leadership, in their staff, the populations they serve and support. I also dream of a world where Independent Living Centers can expand and not be stretched so thin around funding so that Independent Living Centers can be hubs for disability innovation, disability integration, disability rights. Independent Living, I believe, can only really sustain and hopefully grow if we build partnerships with other organizations that inherently have people with disabilities involved, because disability is everywhere. And that these partnerships could evolve into a more unified front so that we can have leadership that is ever-growing, that is sustainable, that's intergenerational, and we can have a world where any person knows about an Independent Living Center and trusts in the services that they will receive there and the social justice, disability rights work that is happening at that center. And I believe it is possible. I believe that there are centers out there that are modeling what amazing solidarity work. There's folks out there, and I think it's coming together and realizing that Independent Living started because we needed each other, and we still do.

ALICE: Thank you, Allie. How about you, Eli?

ELI: You know, everything Allie said. I just think about pride and being proud. And Laura Hershey has the famous poem, "Proud By Practicing."

ALICE: "You Get Proud By Practicing."

ELI: "You Get Proud By Practicing." I'm so proud and honored and privileged to work in this community. It's one of the sources of pride I hold most dear in my life. My entire family is disabled and proud, and it's our identity. And I wanna see a community, in the broadest sense, that's proud of who they are, that's proud of their disabilities, that's proud of their identity, and that shares that pride to the broader community. And the broader community is proud of it, whether you are going into an Independent Living Center for services, whether you work in an Independent Living Center, whether you're a Board member of an Independent Living Center, whether you're a collaborator with an Independent Living Center, whether you're a donor, being proud of the work we do, of the community that we're a part of and sharing that pride with others.

ALICE: Amen to both of you! Aw!

ALLIE: One crucial, empowering element that I've learned from the Independent Living Movement is the spread of disability rights around the world. And it really speaks to the core

truth of people with disabilities leading and supporting one another. And there are Independent Living Movement leaders from Japan serving other nations and doing leadership institutes where they are teaching one another about how to ensure community integration. That is so powerful because just as other countries, including Japan, have learned from the U.S., the Independent Living Movement here has so much to learn from other countries that are really creating powerful peer-run Independent Living Centers.

ALICE: And they're doing it in their own way, which is really, really exciting to see.

ALLIE: Yep.

Wrap-up

ALICE: All right. Well, thank you both so much!

ALLIE: Alice!!

ELI: We love you, Alice!

ALLIE: You're the best!

[hip hop]

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Well, thanks for listening, and I'll see you on the Internets! Byeee!!

♪ Blast off
Stop drop dance off ♪